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Autism in Kenya: A Social, Educational and Political Perspective

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**Autism in Kenya:
A Social, Educational and Political Perspective**

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Kenya: Health and Community Development
Fall 2011

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Abstract

Autism is a widely misunderstood developmental disability that is generally diagnosed in early childhood and has been the recent subject of much media and medical attention in developed nations worldwide. While there has been a noted improvement in diagnostic and therapeutic options for children and their families in developing nations, the attention placed on disability, particularly on autism, is considered underdeveloped and inadequate. This paper will attempt to address the current framework surrounding autism in the area of Nairobi, Kenya and discuss the social attitudes, diagnostic practices, educational opportunities, and government intervention programs available in the area. Given the lack of current research on autism in Kenya, this study was designed to enter the field of autism and break the pattern of a lack of attention and importance placed on those facing autism in Kenya.

Introduction

In developing countries, research and treatment options for children and adults with any kind of disability are just recently being explored. Given the introduction of research on disability in developing countries, there is an incredible gap in available knowledge among both professionals and common citizens leading to a misunderstanding of disabilities such as autism in children and adults. These gaps in knowledge have lead to inaccessibility of diagnostic and treatment services for children with autism as well as a lack of proper government policy to aid these individuals and their caregivers (Maulik, 2007). While Education for All by 2015 is a current policy agenda in 129 developing nations worldwide, it has been shown that children with disabilities are much less likely to be enrolled in school due to factors such as social stigma, parental beliefs about the nature of services, and the inaccessibility of disability services in a given area (Mutua, 2001).

There is a clear need for research in the area of disability in emerging nations and little is known about the cultural perceptions of disability or the receptiveness of the public to various therapy options. Considering that early detection and intervention in many childhood disabilities, including autism, are integral to effective treatment, both public opinion and governmental policy should be informed and altered to accommodate these individuals and attempt to improve diagnostic and therapeutic services (Daley, 2002). It has been noted that given the lack of proper primary health care in many areas as well as the preoccupations with more life threatening childhood illnesses, an emphasis on developmental disabilities in the training of doctors in developing countries is minimal at best. Doctors are noted to be preoccupied with combating basic diseases of poverty such as malnutrition and malaria to name a few. What is not now realized among medical professionals is the

profound impact a developmental disability can have on the future of a child and the importance of early diagnosis and treatment (Darrat, 2008). Africa is particularly behind in these areas and this study will address these gaps in knowledge and practice surrounding autism in Nairobi, Kenya.

Setting

This study was conducted in an around the capital city of Nairobi, Kenya. This urban setting provided a much more forward thinking population than the many rural populations mentioned throughout the course of this paper. In the course of this research, many members of the autism community in Nairobi were found to have moved to the city from rural areas and this is where an insight into rural communities was gained.

This location was chosen for the research presented due to the concentration of special needs resources in Nairobi. While there is still a significant gap in services countrywide, this area had the most professionals in one geographic location. More importantly, parents and educators in this area have been introduced to the term “autism” or “autistic” and this aided in the interview portion of this study considering the study was conducted in one month’s time.

Methodology

The information presented in this study was gathered primarily through informal interviews with professionals in the field of both education and special needs teaching. Interviewed for the study were four special needs teachers, one occupational therapist, one speech and language therapist, two PhD candidates conducting research on autism in Kenya, one pediatric neurologist, five parents of children with autism

and two behavioral therapists. A meeting of Autism Awareness Kenya was also attended in order to better understand the community of parents and teachers working with children with autism and to observe the challenges they face and the breakthroughs that have been made.

This gives a total of sixteen informal interviews or discussions as well as one group discussion with the organization Autism Awareness Kenya. The individuals interviewed were most often spoken to in their own office or workplace. This allowed for the observation of educational facilities and classrooms. The experience of observing special needs classrooms in a functional setting was important to the study and will be discussed in further detail. Interview questions all followed the same general format with variations and more specific questions added based on the interviewees area of expertise. This basic interview structure can be reviewed in Appendix A.

Background Information

Autism spectrum disorder, more commonly referred to as simply autism, can be defined as a group of diverse developmental disorders that have a wide range of behavioral and communication difficulties with varying severity (Rapin, 1997). Professionals have come to characterize the symptoms of autism as a “triad of impairments” that include difficulty in the areas of social relationships, social communication and social understanding. Symptoms of autism, specifically language impairment, are usually noticed between the age of 18 and 30 months in the United States and other countries with quality autism programs. This is generally when a team of professionals is able to diagnose a child with autism and begin early

intervention therapies that produce the best outcome for the child's future as a functioning member of society.

The concept of a spectrum in the realm of autism has presented a challenge to medical professionals and treatment centers currently tackling diagnosis and treatment in the field. Many individuals diagnosed with Asperger syndrome, a developmental disability on the autism spectrum, may have much better verbal skills than an individual diagnosed with a different form of autism or pervasive developmental disorder. Some individuals with autism may also be more susceptible to behavioral and language therapies and thus more easily able to adapt and understand societal conventions. These children, most probably after therapeutic interventions, can become well able to lead independent lives and begin families of their own. Many children diagnosed with more severe forms of autism, however, may never gain this desired functionality and will exhibit more stereotypical autistic symptoms such as the inability to form social relationships or properly communicate with the world around them.

While the exact cause of autism is unknown, theories and scientific evidence point to a combination of factors such as genetic, prenatal, and postnatal components of child development. In developing countries such as Tanzania, cases of autism have been noted to appear after a particularly traumatic case of childhood malaria or rheumatic fever and this has been a confirmed source of autism following scientific research (Mankoski, 2006). Other researchers are more convinced by the genetics behind this developmental disorder and through monozygotic twin studies it has been found that when there is a diagnosis of autism, there is a 90% chance that both twins will present with some form of the disorder (Rapin, 1997). Nutrition, poverty, and proper child development has also been researched in the developing world and

considered a probable cause of autism in children. The cycle of poverty, poor maternal health and poor child nutrition is believed to stunt cognitive development and lead to developmental disorders such as autism (Walker, 2007). Other sources of etiology such as prenatal development are not as clearly understood and research in this area is currently being conducted (Claassen, 2008).

The lack of clear etiology has led to many misconceptions surrounding what exactly qualifies as autism, given the wide range of impairments and functionality from child to child. This variation in each individual presents a unique challenge to those armed with the task of treating children with autism. While there are many different therapies available such as speech and language therapy and behavior analysis, every child will without a doubt respond differently to various combinations of treatments. A trial and error method of intervention is most often recommended by physicians and autism professionals in order to pinpoint the most effective option for an individual child (Callahan, 2010).

Despite the wide range of available treatment options, there is no doubt among professionals that early intervention will yield the best results in each and every case of autism. Early intervention can be defined as treatment programs that begin before the child reaches the age of five due to the increased brain plasticity and ability to acquire communication and behavioral skills (Erba, 2000). The desire to limit the number of children forced to battle lifelong impairments is the driving force behind early intervention programs and almost every child that receives a diagnosis in developed countries will begin therapy before the age of three. Doctors do their part in diagnosing children at an early age and refer them to proper therapeutic options before the target of five years (Kasari, 2002).

A treatment option with a particularly impressive record of effectiveness is Applied Behavior Analysis or ABA therapy. This is the only current treatment option for children with autism that is backed by scientific results as well as a set of data on each child undergoing therapy in order to thoroughly chart individual progress. ABA therapy has the unique ability to break down a social skill that the therapist would like the child to learn and teach that skill one step at a time until it is mastered. This method allows data to be collected on which skills can be acquired and how quickly each particular child can achieve this. Children in ABA therapy will learn social skills and conventions that were once alien to them in this systematic way (Fortunato, 2007).

ABA and another therapy called Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) have been noted as the most commonly utilized and requested forms of autism therapy in both the public and private sector in the United States (Callahan, 2010). Both of these methods are evidence-based and have been the subject of much research in the field of special education. Other therapies such as occupational therapy and speech and language therapy have been noted as integral to the acquisition of life skills and verbal functionality in children with autism and are regularly used as proved treatment options. This combination of various treatments is a common recommendation in order to create a more complete and fluent set of skills in a child with autism.

Knowledge of Autism in Kenya

It has been calculated that anywhere from 60 to 75% of the world's population with a disability lives in a Third World nation and 10% of these individuals are children of school age. This is undoubtedly a significant portion of the world's

population, however, few resources are allocated to this group of people (Mutua, 2001). The neglect of these individuals worldwide has led to the lack of accurate prevalence data in countries like Kenya. Diagnosis is very often unattainable and when a cursory diagnosis is made, these numbers have no official place to be recorded and instead go unnoticed. With a lack of prevalence data comes the inability to properly accommodate these individuals and allow children with autism to attend public school or receive proper medical attention (Interview A4, A11).

The lack of professional attention placed on disabilities such as autism has not helped the country move forward in terms of awareness which would undoubtedly create more widespread services and social acceptability for children in Kenyan society. Researcher Jon Onala has estimated that given current world data on autism prevalence and the population of Nairobi, an estimated 25,000 children are affected by a disorder on the autism spectrum in this area alone (Interview A5).

The relatively new field of autism and developmental disabilities in Kenya has lead to an influx of both accurate and inaccurate information available to parents, teachers and medical professionals. Contradictory information as to the causes of autism, the most effective treatment methods and the potential for rehabilitation from the disorder are all areas of misunderstanding that I have come across throughout my research in Nairobi.

While many are still in the dark about the nature of autism, two notable organizations have been created to attempt to fill the gap in public knowledge and create quality services and support systems for children and families dealing with autism. The Autism Society of Kenya and Autism Awareness Kenya were both started by parents and educators to close gaps in understanding and open up possibilities for children with autism. Both societies stress the importance of media

coverage and public outreach trainings to improve overall autism awareness among the Kenyan public and both have successfully held public events such as awareness walks and car wash fundraisers to run programs. Parents participating in the events, however, note that there is still a long way to go in terms of countrywide awareness and the provision of services for their children (Interview A9).

Every member of Autism Awareness Kenya that I spoke with discussed a perception of alleged witchcraft and sorcery that accompanies the display of autism symptoms, especially in more rural areas of Kenya. It is this lack of understanding that prevents parents from searching for proper medical care or a proper diagnosis of autism spectrum disorder. Parents in many parts of Kenya will instead resort to hiding their children in a back room or confining a child to the home (Interview A7). This ultimately prevents any kind of social or verbal improvements and will permanently diminish the effects of future attempts at intervention. Studies have indicated that families served with proper information about disabilities can use their faith as a source of empowerment instead of discrimination for both the affected child and other family members. In this way, families were able to obtain proper treatment as well as the emotional unity and support required to proceed with the difficult path to treatment and intervention (King, 2008). This is not the case for many Kenyans, however, as they instead find their faith a source of exile and persecution in their communities with no resources to help their children with autism.

Impact on Family Structure

A notable impact on family structure and unity was mentioned in discussions with members of both organizations as well as interviews with educators in the field. Given that a diagnosis of any type of illness is often blamed on the mother of the

child, interviewees noted that oftentimes mothers are left alone to provide for their disabled child without support from the child's father due to a deep-rooted family belief in sorcery or witchcraft. Many fathers are said to fear the potential birth of another child with autism and the community generally supports abandonment in these cases. Not only will this leave the family in a dire financial situation, but it further diminishes the possibility that a mother will seek and find appropriate intervention for her child with autism. These children are most often taken to local village witchdoctors for treatment to rid them of their evil spirits or familial curse. Oftentimes children can be subjected to painful and unethical medical practices to appease family members and attempt to mend damaged social standing or public image (Interview A7).

Families of children with autism suffer from the added burden of not understanding the exact cause or prognosis of their child's condition and this adds an immeasurable amount of stress to the daily lives of caregivers. A study conducted in Kilifi, Kenya noted that caregivers of children with autism are forced to face emotional stress, guilt, financial hardships, and disrupted family relationships. The added perception of children with autism as possessed or cursed in much of Africa only worsens an already difficult family environment (Gona, 2010).

It is stressed in most developing communities that in order to lead a so-called "normal life" the individual must be a functioning member of both the social and economic aspects of society. If this potential seems unlikely, investments in proper education or expensive therapy and medicines are seen as wasteful and unnecessary. Parents of handicapped children are faced with this decision and in many areas of Kenya they will more often choose to invest in able-bodied children rather than attempt to finance treatment for a disability like autism. Without the access to

accurate information and affordable treatments, this will continue to be the outcome in communities throughout Kenya due to a perceived lack of potential productivity (Moriyama, 1974).

Knowledge among Medical Professionals

The lack of autism awareness in Kenya is also easily observed among medical professionals in many areas of the country. Doctors in Kenya do not undergo training in developmental disabilities such as autism unless they choose a specialty such as neurology or pediatrics and even then, training is considered minimal at best. Faculty at The Aga Khan Hospital are lobbying administration to create a training program for all medical personnel in developmental disabilities to diagnose autism more accurately but current medical school graduates are still entering the medical field without this essential training (Interview A4). However, doctors who have been informed about the signs and symptoms of autism are noted by educational professionals to be misdiagnosing autism in children who are simply hyperactive or faced with delays in verbal skills. This misdiagnosis brings turmoil to families and causes unnecessary emotional and financial burdens for these affected families (Interview A12).

These misconceptions of autism among medical professionals are not correcting the current influx of inaccurate information plaguing the Kenyan public and are instead adding fuel to the fire. Parents in Kenya are very often advised to follow a gluten and casein free diet to improve behavioral problems and ameliorate the classic symptoms of autism. While children with autism do sometimes present with irritable digestive systems and can benefit from this type of diet, it is by no means a cure for all children with autism. Parents advised to follow this diet often

must take great financial sacrifices to do so considering the prices of gluten free products and specialty milk options (Ametepee, 2009).

Autism Diagnostics and Treatment Referrals

Symptoms of autism usually become apparent to friends and family members when an affected child reaches the age of 18 months and fails to achieve normal verbal and social development landmarks. In Kenya, the medical and educational professionals interviewed stated that the average age of diagnosis is between three and four years due to the lack of available resources for families (Interview A4, A7). Parents said that they noticed their children were not following a routine developmental pathway but they did not know where they could go to get their child diagnosed (Interview A3). Many medical professionals often inform parents that their children will soon acquire language skills, outgrow their hyperactivity and begin to interact with other children as expected. When these children never do grow out of their impairments, parents seek out anyone who can properly recognize and diagnose their child, often bringing them to major cities such as Nairobi, Kisumu or Mombasa where the only autism specialists in the country currently reside. This very common chain of events of autism diagnostics in Kenya significantly shortens the amount of time available to find and begin appropriate early interventions and undoubtedly has a negative long-term effect on child development (Interview A8).

A government funded program called Educational Assessment and Resource Centers (EARCs) is a public works project aimed finding and referring children with disabilities to proper treatment facilities. Established in the 1980s, Kenya had 139 EARCs, equivalent to one for every district in Kenya. There are now more districts in the country but these centers still remain. Their purpose is to go into rural

communities to assess children and hold workshops to inform community members about childhood disabilities like autism. These centers are a resource for the urban community and are a known public center to turn to when a family is ready to seek a diagnosis for their child. After visiting an EARC based out of Kenyatta National Hospital in Nairobi, I noticed that the EARC is armed with the task of referring children with any sort of mental or physical handicap to a proper program and are most likely not required to ensure this child receives proper treatment. Their sole purpose is to refer children to a center with the hope that their parent will pursue this educational option (Interview A11).

A study conducted in Bondo, Kenya set out to measure the efficacy of the EARC screening program in the area. It was found that the EARC screening method could adequately confirm the existence and assess the degree of disability within a child but that this efficacy was most often limited to children with severe disability. Excluding a child with a more mild form of disability may be preferred by family members to avoid community stigma but will ultimately lead to more noticeable complications with this disability in the future (Muga, 2003).

Despite the creation of EARCs throughout Kenya, diagnostics in the field of autism are still considered to be limited to urban areas, particularly within families of higher socioeconomic status. This lack of proper diagnostic data stems from a deficiency in knowledge of developmental disabilities and autism countrywide. The only quality schools, treatment programs, and medical professionals trained to work with children with autism are restricted to areas like Nairobi or Mombasa, leaving the rest of the country without the resources to treat and educate their children with autism (Interview A8). Concentration and exclusivity of services in urban areas is a

place where Kenya can seek to improve its services to families nationwide and produce a better outcome for children with autism and their families.

While diagnostics in countries such as the United States are required to be conducted by a team of professionals, this is not the case in Kenya. Individuals who would be considered unqualified to diagnose autism in other countries are given the task of making a final diagnosis in Kenya. These individuals include teachers, occupational, and behavior therapists. Evaluators most often use diagnostic tools developed in the United Kingdom that do not often transcend cultural barriers and thus complicate a clear autism diagnosis (Interview A5). Because of this combination of factors, autism is often over diagnosed due to the misunderstanding of symptom presentation or under diagnosed in areas where autism is not a well known disability. More and more often, local EARCs are forced to make a diagnosis when this was not their original purpose. EARC evaluators are some of the most familiar people in the country when it comes to developmental disabilities but this is an unconventional diagnostic method that would not likely be accepted in more developed nations (Interview A12).

On a visit to The Aga Khan Hospital in Nairobi, I met with pediatric neurologist Dr. Pauline Samia to talk about her work with children with autism. Dr. Samia holds frequent clinical hours where she is able to assess and diagnose children with disabilities at Aga Khan. She reports that the clinic see somewhere from two to four new cases of autism each day and by default, she takes on their case to ensure proper treatment continues after they leave the diagnostic clinic. She noted the overall lack of coordination of care in most cases when diagnosis is not usually followed by proper referrals or treatment acquisition. It is Dr. Samia's personal mission to ensure that she refers these children to available occupational and speech and language

therapists as well as schools with special needs accommodations or autism units (Interview A4).

Educational and Therapeutic Options

Education in Rural Areas

The most important barrier to access of therapy and education is a family's location within Kenya. Families with children living in rural areas are more likely to raise a child with autism without ever receiving proper diagnosis, and even if they did, it is likely there would not be a treatment center located near their home. If a school in a rural part of Kenya does happen to have a special unit, this classroom will most probably be full of children, each with a unique disability, taught by a teacher with minimal training in what Kenyans call "special needs education." These teachers are unable to give each child the individualized lesson plans they will require to learn and succeed despite the best intentions of the teaching staff (Interview A8).

A study conducted in Kenya identified a rural upbringing as a significant risk factor for developing a neurological impairment. The study found a disproportionate number of children with moderate to severe epilepsy as well as impairments in hearing and cognition. The researchers in this study attributed these high numbers to an increased burden of childhood illness in rural areas of Kenya as well as a lack of resources such as proper nutrition and sanitation that may all lead to these impairments while a child develops in such conditions (Mung'ala-Odera, 2006).

Rural areas in Kenya are also currently without any speech and language therapists (SLTs) whatsoever. An American certified SLT informed me that there are about ten total SLTs in the entire country, all of whom work privately with some volunteer service in their spare time. Given the communication and verbal

impairments present in most cases of autism, regular speech and language therapy is imperative to the development of language skills as the child matures. Without these SLTs across the country, unqualified individuals are attempting to prompt a child to communicate without much success and most likely do more harm than good. Fortunately, many universities in the Nairobi area are rumored to be developing a graduate program to certify speech and language therapists to work with children in Kenya. This would most likely continue to supply SLTs to the private sector but it will nonetheless make a dent in SLT availability for children with autism (Interview A8).

Children in high versus low-income households, often inaccurately thought to be synonymous with urban versus rural families, also have very different access to autism and educational services. Most autism services in Kenya are available in urban areas if a family is willing and able to pay the fees that accompany private and specialized services, usually administered by Americans or Europeans living and working in Kenya. Most of these individuals are certified specialists in the field of special education and administer more western therapy options such as behavior therapy, occupational therapy, applied behavior analysis and speech and language therapy. While this influx of professionals is a step in the right direction for the treatment of autism in Kenya, these services are still considered a luxury for many families and most are unable to pay the high price for private services.

To attempt to mediate this gap in availability of services, a society called Special Education Professionals (SEP) was created. This organization gives these qualified professionals an opportunity to volunteer their time and quality services to families in low-income or rural areas of Kenya. Not only do the professionals from SEP provide services to children in these areas but they also sponsor training forums

for parents in these areas to heighten awareness and educate the general public. Additionally, they hold trainings for young professionals with the hopes of pursuing a career in the field of special education. While this is not an internationally recognized certification, the hands on learning experience is of great value to these students and will be put to good use throughout the country treating children with autism who would have otherwise foregone these services (Interview A2).

An autism professional I spoke with during my study mentioned that many Kenyans currently pursuing higher education are not encouraged to enter the field of special education and see little incentive for doing so. These specialists are forced into the private sector to compete for clients and it is a daily battle to make ends meet, even when practicing in the high-income areas of the city of Nairobi. Multiple autism professionals have mentioned that more of an incentive on the part of universities and government agencies should be placed on specializing in these fields in order to both create jobs for recent graduates as well as increase the availability of services for children with autism. It seems that individuals working in this field are currently those with a personal passion and a desire to fill the gaps in this underserved sector of educational services in Kenya (Interview A7).

Public Education

The public education option for children with disabilities, including autism, in Kenya include what are referred to as “special needs units” and in one case, a specific “autism unit.” These units are set-up as single classrooms within primary schools generally equipped with two to three special needs teachers for a classroom of 30-40 students. The problem with these units, specifically concerning children with autism, is the lack of individual attention that can be placed on each child to ensure they are

learning to their fullest potential. City Primary School is the one school in Kenya currently furnished with an Autism Unit that serves approximately 98 children with only three trained personnel equipped to educate children with autism (Interview A1). While it is important to have a place for children with autism to receive a public education, the center must be able to accommodate and provide for all students and this student to teacher ration does not seem conducive to a productive therapeutic or learning environment (Interview, Mbagathi Special Unit).

Government schools have begun to employ an inclusive education model rather than a special needs unit system in order to increase the learning potential of children with disabilities like autism. Multiple studies have shown the benefits of integration into mainstream classrooms that give children with special needs access to heightened social environments and elevate their potential to learn on grade-level with their peers (Wendelborg, 2011). Currently, most of the special units in Kenyan public schools serve as infrequent feeder pools to mainstream classrooms within a primary school when children seem ready to be integrated. This allows children who have succeeded in a special unit to move on and enhance their learning experience outside of a special unit that may seem stifling to students who are able to learn more quickly than others. This, however, does not address the potential of other children in the unit such as those with autism who would greatly benefit from the social and behavioral models they could observe in a regular classroom. It is proven that when children with autism are exposed to environments with children without disabilities, they are more likely to acquire social skills and participate in activities (Brantlinger, 1997).

The training of special needs teachers in Kenya occurs at a government institute called the Kenya Institute for Special Education (KISE). After speaking to many of the privately certified and foreign educators specializing in autism, I was

informed that training provided by KISE was mediocre. Reports said that the program was not thorough and that teachers left the certification program with a generalized training in “special needs” without ever learning too many specifics about each individual disability. Teachers who emerged from the program gave the KISE training a slightly better review but said most of their methods were learned after they were given a special needs classroom of their own to teach. This experiential learning is important to find your own strengths as a teacher but it is also detrimental to students like those with autism who have a complicated set of impairments that an educator should be familiar with before attempting to teach these children in a classroom (Interview A12).

Private Education and Therapeutic Services

Though the lack of adequate services for children with autism was apparent in the research conducted in the Nairobi public sector, quality treatment centers do exist in Kenya and should be commended for their work. An example of such a place is Kaizora Consultants in the Karen neighborhood of Nairobi. Kaizora Consultants is a private treatment center and the only center specializing in Applied Behavior Analysis (ABA) in Kenya. Pooja Panesar founded Kaizora and found she had a passion for teaching children with autism who otherwise would go without proper treatment. Panesar learned to use ABA therapy through on site training but was the recipient of a scholarship to The University of Massachusetts - Boston to receive her official board certification. At the end of the year when she becomes certified, Panesar will be the second educator in all of Africa to receive her certification in ABA therapy. Kaizora is currently treating five children with this evidence-based therapy and is expanding

its program to a full day school in January 2012, when it will be able to accommodate up to ten children.

A major problem with therapy centers that treat children with autism is their part-time nature where a child is engaged in a session for about one to two hours per day. This creates a very real logistical and financial issue for parents wishing to enroll their children in a school program that does not accommodate this type of treatment. Panesar is looking to solve this issue with her full day program by incorporating other therapeutic methods into her full day program to act as a school rather than a treatment center. This will solve the problem of the children at her center forgoing a traditional education for their much-needed ABA therapy each day (Interview A7).

A second and more non-traditional school for children with autism is being developed not far from Kaizora in Karen. A school called the International Integration School is currently run by principal Godfrey Wamoyi with the hopes of creating highly functioning members of society. The theory behind the program is that adolescents and adults with autism can, contrary to popular belief, hold jobs and contribute to the economic sector of society. The International Integration School provides a traditional secondary education including math, social skills, and language but also incorporates elements of crop cultivation and woodwork in order to teach the students a useful and profitable trade. These students are of secondary school age and most of the traditional autism therapies have stopped at this point and traditional education has intensified. Currently, the school has a garden that markets lettuce and other produce to major supermarket chains as well as chickens and pigs to breed and sell.

The project has the hopes of becoming a self-sustaining business in the future with graduates of the school becoming the first employees of the company. Not only

will this create a place for adults with autism after completion of an academic program but it will also increase their value and contribution to the Kenyan society. The one problem with this system is the investment a student must originally make to be able to attend the school. Wamoyi has high hopes for the project and insists that it will be profitable but the initial acquisition of funds and students has thus far proven difficult with only fourteen students enrolled (Interview A10).

Children with autism from families with the means to afford private therapies most often look to use as many different types of therapy as possible to attempt to maximize the positive results of the individualized therapy. While a combination of therapy is a way to see improvements in both behavior change and communication skills, the problem with this approach in Kenya is the copious amount of misinformation available to families of children with autism. Among the parents interviewed for this study, four out of five have been sold expensive drug therapies promised to calm their child's hyperactivity and improve their social behavior skills. This most likely follows the misconception that a child with autism can be treated similarly to those children with a disorder such as Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD), which is not the case (Interview A9).

Kenyan parents are particularly prone to purchasing expensive drug therapies due to the cultural belief in this treatment over a behavioral or occupational therapy. A general observed mentality among these Kenyan parents is the belief in a pill or injection to calm their child and prompt them to speak rather than a faith in ABA or occupational therapy for one or two hours per day (Danesco, 1997). Two of the parents interviewed reported that while the drugs are imported, very expensive, and have not help their child's hyperactivity, they are continuing to administer the drug in

the hopes that it will soon begin to take effect. One parent reports the wish to invest in the development of an injection that can be administered to children with autism that will have a long lasting therapeutic effect rather than a daily oral dose of the medication (Interview A9).

Government Provisions for Individuals with Autism

The Kenyan government created and instituted a new constitution in the year 2010 that had multiple rights reserved for individuals with disabilities living in Kenya. In addition to these outlined provisions, the recent initiative entitled Education for All by 2015 outlines the benefits and requirement of an education for all children, even those with disabilities like autism.

In Chapter Two, Section Ten of the Constitution of Kenya the government states, “the national values and principles of governance include – human dignity, equity, inclusiveness, equity, social justice, human rights, non-discrimination, and protection of the marginalized.” Based on the evidence collected, I have found that children with autism and their families are indeed denied these rights of “inclusiveness, equity, and non-discrimination” as part of what could be considered a “marginalized” group of individuals. The government should follow up on this statement and govern with these groups in mind rather than ignore obvious gaps in educational and medical services for people with disabilities (Constitution, 2010).

In another portion of the Constitution of Kenya, Chapter Two Section 53 outlines the rights that children are entitled to as citizens of Kenya. These include what is referred to as “free and compulsory basic education.” It is known that many children of school age in Kenya do not attend school because of required uniforms, school fees and other complications but the main reason cited by parents of children

with autism for not sending their children to school is the lack of accommodations for their child. In a public school system, classrooms and teachers for these children should be provided under this constitution that are conducive to diverse learning needs and limitations.

The third and final section of the Constitution of Kenya that requires attention in this matter is the Persons with Disabilities Act. This act is contained within Chapter Two Section 54 of the Constitution and says the following:

“A person with any disability is entitled –

- (a) to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning;
- (b) to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person; ...
- (e) to access materials and devices to overcome constraints arising from the persons disability.”

While this Act does not explicitly differentiate between the many different types of disabilities, one can assume that these accommodations are required for children with both mental and physical handicaps. Once again, access to proper education is clearly mentioned as a right of those with disabilities. This promise has not yet come to fruition in practice (Constitution, 2010).

Given reports from the participants of the study it is clear that in both a social environment and an educational setting, children with autism and their families do not enjoy the provisions that have been laid out in the Constitution of Kenya. The question now becomes what the government is currently doing to provide these services for people with disabilities to fulfill the promise of equal access and equal rights outlined in this document.

The Framework

A second government document titled The National Special Needs Education Policy Framework more explicitly outlines Kenyan policy on special education. Published by the Kenyan Ministry of Education, the framework notes that a quality education for people with disabilities is essential for potential self-reliance and employment opportunities. The goal of inclusive education for all by 2015 is mentioned in the document, which most professionals believe to be important for the academic and behavioral growth of children with autism and other disabilities. Importantly, this document points out the flaws of the current Kenyan education system and notes that most children with disability in Kenya are both illiterate and unable to access quality education through the public sector.

The framework makes four recommendations for improving the current special needs educational structure that include:

- (1) The training of more special needs teachers
- (2) The improvement of the national EARC program
- (3) A national census to determine the number of children with special needs
- (4) The creation of barrier-free special needs schools to create better access on all socioeconomic levels.

These recommendations would indeed solve many of the educational issues plaguing children with autism in Kenya. The only issue in this framework is the actual implementation of these recommendations. Acquiring the appropriate funds per child and creating the infrastructure for this policy will most likely be a long process that will not proceed without much prodding from parents and activists speaking on the part of children with autism and other disabilities.

The promise of free primary education for all has clearly not been realized and this framework cites the improvement of disability services as the key to greater national productivity and equity for children with disabilities. Recognizing this gap

was a first step for Kenyan administrators and the Ministry of Education but implementing this policy is a challenge that will only be realized in time and after much advocacy in favor of children with disabilities (Ministry of Education, 2009).

The Problem

Lack of accurate information circulating in the public arena seems to be the most important barrier to the creation of both positive social perceptions and educational opportunities for children with autism. Parents are bombarded with wrong information from community members when children present with the symptoms of autism and are unable to receive proper information if parents seek a diagnosis for their child. This is the root of the problem surrounding autism in Kenya and correcting both these misconceptions and an overall lack of understanding is a lofty goal. Debates as to what the most effective method of outreach is for Kenya have been had but I believe the secret lies with the parents of these children with autism. These individuals have the greatest potential to create change in the three areas that matter most: social understanding, medical professional training, and the provision of quality services from the public sector.

Children who live in communities where their disability is seen as a familial curse are at the highest risk for isolation, abandonment, and a life without proper therapy to treat their autism. The lack of social understanding is a problem throughout most parts of Kenya, even in more advanced and developed urban areas such as Nairobi. A lack of social understanding is seen here among communities and religious groups that do not understand the complexities of a disability such as autism and choose witchcraft as a satisfactory explanation. To avoid humiliation, parents will

keep their children with autism in a secluded space within the home to limit exposure to community members and preserve the family name.

A second problem area for the service of children with autism in Kenya is proper diagnostics. Information on diagnostic services must be improved among the general Kenyan population and medical professionals should be required to undergo proper training to better notice and diagnose autism in children at the earliest possible age. Diagnosing at an average age of three to four years and foregoing treatment until the child is of school age is not an effective method of realizing the full potential of these children. Improved diagnostics is the best way to start much-needed early intervention programs. Sources of this diagnostic problem are rooted in the pediatric care framework where primary care check-ups may not happen at regular intervals where medical professionals would be able to recognize these changes in a developing child. The second problem in this discipline is the lack of training of medical professionals. Currently, when a worried family comes to a hospital with their child, none of the doctors are familiar enough with autism to make a proper diagnosis. These are all reasons why diagnosis is extended and treatment does not occur before school age.

The third and final problem area identified by this study is the lack of available provisions in education and treatment for children with autism by government agencies. Kenya has in place both a newly created constitution, Persons with Disabilities Act and a National Special Needs Education Policy Framework and yet widespread services are not available. Within The National Special Needs Education Policy Framework, various challenges to achieving the goal of inclusive education for children with disabilities are outlined. These barriers include:

- (1) Inadequate data on children with special education need and disabilities,

- (2) Lack of a comprehensive policy on Special Needs Education and proper guidelines on mainstreaming of special needs education at all levels and in the country.
- (3) Lack of appropriate tools and skills for early identification and assessment;
- (4) Inadequate physical infrastructure, teaching/learning materials and facilities appropriate for special needs learners
- (5) Inadequate skilled manpower and inappropriate placement of children with special needs and disabilities.

This very clearly and thoroughly outlines the five major barriers in implementing this policy and the necessary improvements in infrastructure that are required to make these changes to the national system of education (Ministry of Education, 2009).

Although the Ministry of Education has good intentions with the publication of this document as well as the ratification of Education for All by 2015, it seems a lofty goal given the current situation in Kenya and the absence of such important pieces of this puzzle (United Nations, 2008).

The Solution

While it is obvious that there is not one clear path to the creation of services for individuals with autism in Kenya, there are steps that could be made on all levels to improve the current framework and pave the way for service creation in the very near future. All three areas discussed in this paper (social understanding, educational and medical services and government provisions) could drastically be improved if some key structures and beliefs were altered within Kenya.

In terms of awareness and social understanding, activism and exposure are the two most important ways to improve in these areas. This has been effective in the United States where major media personalities have been able to gain access to television programs and mass media campaigns to improve awareness as well as raise funds for the research and development of autism programs. Advocacy on the part of parents and educational professionals as well as the few doctors working in the field

of pediatric neurology and disability will be able to create change and awareness in their communities. This would require a battle against stigma and the engrained social attitudes that currently prompt parents to hide their children and withhold medical attention. While it will not be an easy road to social understanding, it is indeed a battle that must be fought by the individuals most familiar with the disorder for the rights they long to achieve. No other organizations have the same passion or need for social equality or proper provisions for these children (King, 2008).

The solution to the conundrum of training professionals to work with children with autism seems to be importing trainers and educators from developed nations for the time being. This would be a temporary solution until there are enough in-country certified professionals for Kenya to train their own autism and special needs teachers. Out of the eleven professionals I interviewed, only four of them were Kenyan natives and all of these Kenyans received higher education in Europe, the United States or Canada. Foreign aid and influence have had a very important role in this discipline and all interviewees cited this as the key to developing high quality and widespread services for people with autism in the future. Organizations like the Global Autism Project based out of Brooklyn, New York were created with this very goal of providing training and guidelines for the treatment of autism in developing nations. The Project is currently working with special education centers in Ghana, India, and Kenya to provide ABA and behavioral training for staff members and to encourage the provision of services in low-income areas of these host nations (Pinney, 2011).

Foreign aid institutions like the Global Autism Project are important to diffusing information on disabilities like autism to developing nations in order to expedite the creation of services in these countries. Without the help of foreign aid,

many centers would still be without the information needed to properly approach the education and treatment of children with autism in countries like Kenya.

Last is the problem of securing government services for children with autism, most importantly accommodations within public schools. The government has recognized its short comings in providing services for children with disability in the field of education and the final step for the Kenyan government is actually implementing the plan outlined in The National Special Needs Education Policy Framework. The barriers to intervention and necessary changes to be made were thoroughly identified but little to no change has been seen anywhere in Kenya. Again, the government should be held accountable for its lack of action in terms of provision of services to prompt change to be created.

The agencies responsible for education and special needs are aware of the changes that must be made and the services that must be improved but the supposed lack of funding and incentive are keeping the outlined plan from becoming reality. If this framework were to be carried out, thousands of children nationwide would have access to services, hundreds of teachers would receive valuable certifications and countless communities would be better educated on the truth behind developmental disabilities like autism. The government has the plan to build a future for children with autism; all that is left is the implementation.

Areas for Additional Research

Given the minimal amount of research on autism that has been conducted in Sub-Saharan Africa as a whole, there are many specific areas that this study was not able to research in depth (Daley, 2002). The exact practices and attitudes in rural areas would be an interested study to conduct in depth from within these communities.

Given the one-month time span of this study, I did not think traveling to a rural area would produce much information without a large amount of preparation work involved. This study relied on the testimonies of individuals who had personal experience with these rural communities but I believe following a family with a child with autism would provide a good amount of insight on attitudes surrounding autism.

The plausibility of westernized therapy options would also be an interesting study to conduct in order to assess the types of therapy the Kenyan public is most receptive to and which would be easiest to implement in the Kenyan setting. There is no doubt that services should be altered and developed to be more inclusive and individualized but research on how this should be conducted is an important first step to make before investments are made in implementation.

The efficacy of training programs for special needs teachers is an area that the government and Ministry of Education would greatly benefit from in order to specially train more teachers in this field. There does not seem to be much quality control in the training program for special needs teachers and this could greatly increase the worth of public education received by children with autism and other disabilities in a classroom setting. In order to attempt to provide services for children with disabilities in public schools, the quality of teaching should be a concern for all parties involved to make the endeavor worthwhile and effective.

The impact and effectiveness of awareness campaigns should be conducted in order to better introduce this information to the Kenyan public. Mass media campaigns would make an incredible difference in terms of widespread awareness and social understanding but the best possible medium should be chosen to circulate this information effectively. Testing should ideally occur in all parts of Kenya given the vastly different income levels and accommodation of technology throughout the

country. After this research is conducted, it may be easier to allocate both government and donor funds to begin campaigns and educate the public on autism and other disabilities on a wide scale. As mentioned, this would not only increase social understanding but perceivably also make a sizable dent in diagnostic rates after parents are educated on the signs, symptoms, and treatment options of autism.

Finally, a study of the perception of disabled individuals in terms of investment and public aid attraction would be an interesting project. Many have noted that foreign investors and family members are not likely to invest in disabled individuals when money could instead be directed to able-bodied individuals with a higher perceived potential for productivity. A study on why this attitude exists and if there is much truth to this perception would be useful for those in the non-profit and aid world to better create fundraising campaigns and design treatment programs.

Conclusion

A therapist and educator working with children of autism said in her interview, “children with autism are expected to live in our world when they understand a world of their own. Why do we expect this of them? They just need some extra time to learn about our world” (Interview A7). Children with autism have a different way of learning and they are not often viewed in this manner by much of the Kenyan population due to a lack of awareness, social understanding and developed services throughout the country. Through the interviews and participant observation conducted to complete this research, I have gained insight into the world of autism and the serious gaps in quality services available to children with autism. The country has taken a crucial step in the right direction and has institutions providing private autism therapy as well as the structure to implement an inclusive

special education program in the near future. Education and proper therapy is the only way to achieve communication skills that parents desire and behavioral skills required for an adult to function independently in society. The barriers to these services are clear and primarily fall on the inefficiency of public education projects and the lack of proper training for teachers and medical professionals. The conundrum of accommodating children with autism in Kenya can be linked to three crucial areas that must be remedied in this general sequence: awareness of autism and its presentation, training of medical professionals and teachers to diagnose and treat autism, and the provision of disability services on the part of the government. Through the progression of these steps, Kenya can be on its way to providing a nurturing rather than an alienating environment for children with autism and their families.

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Appendix A: General Interview Questions

Attitudes

1. What is autism?
2. Describe autism.
3. Why do children have autism?
 - a. What does the public think?
4. Where does autism come from?
 - a. a. What does the public think?
5. Can autism be cured?
6. What do Kenyans call a child with autism?
7. What do you do when a child has autism?
8. What do other people think of children with autism?
9. How can awareness be improved in Kenya?

Treatment

1. Who most often diagnoses/notifies autism first?
2. Who treats autism?
3. What does autism treatment consist of?
4. What training to autism specialists have? What makes them qualified?
5. Are you trained to work with children with autism?
 - a. Where were you trained?
 - b. How many years was your schooling?
6. What are the educational services available both public and private?
7. What training to medical professionals receive in order to diagnose autism?
8. What is the prevalence of autism in Kenya?
9. Do children on all parts of the spectrum receive treatment?
10. What is the main barrier to diagnosis?
11. What age is autism usually noticed?
12. After diagnosis, when does treatment start?
13. What are your thoughts on Early Intervention treatment?
14. How could diagnostics be improved in Kenya?
15. What is the purpose of assessments? How are they used?

Government Policy

1. What does the Kenyan government provide for individuals with autism?
2. What do you think the government should be doing?
3. Do you see a change in awareness countrywide?
4. Do you think the government will ever provide provisions?